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ABSTRACT

A research project in Australia investigated the support and service needs of 47 parents (40 mothers and 7 fathers) with intellectual disability. The study involved interviews and questionnaires with parents, significant others, and service workers; focus groups; and a survey of generic service providers. Findings indicated that 63 percent of parents reported needing help with child care and development; 58 percent needed support in the domestic area of money management; 50 percent needed help with using community resources; and 45 percent needed help with vocational skills/training. Parents also expressed a need for help with friendships. Additionally, the study found that parents, significant others, and service workers were generally consistent on the help they thought parents needed. Service workers reported such concerns as a lack of time and high caseloads and an inability to provide the practical day-to-day help parents need. The study resulted in eight recommendations: (1) intensive, individualized support; (2) on-going funding; (3) family-centered focus; (4) accessible, available services; (5) supportive environment for parents; (6) interagency collaboration; (7) data collection; and (8) a pilot project on interagency collaboration. (Contains 10 references.) (DB)

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SUPPORT AND SERVICE NEEDS OF PARENTS WITH INTELLECTUAL DISABILITY: PARENT PERSPECTIVES

ED 402 715

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Introduction

In Australia, the number of parents with intellectual disability is increasing - and there is growing interest in providing support to these parents. Deinstitutionalisation has provided the opportunity for people with disabilities to live more ordinary lives in the community. Recent federal and state legislation mandates that people with disabilities be given every opportunity to participate as full citizens in Australian society. Becoming a parent is one aspect of full citizenship.

From the literature, we know that some parents with intellectual disability will need a lot of help in raising their children and on an ongoing basis, while others may need only short-term, intermittent help (Llewellyn, 1990). Like all parents, parents with intellectual disability have a wide range of parenting capabilities that vary according to their own experiences in a family setting, their knowledge and skills in caring for children, and their personality style.

Federal and State disability policy in Australia promotes mainstream agencies as the preferred option for service delivery to people with intellectual disability. This means that services used by people with disabilities are to be part of local coordinated services that are generally available to other members of the community (Llewellyn, 1994; Llewellyn & Brigden, 1995).

To ensure that mainstream services can adequately meet the needs of parents with intellectual disability, we need first to find out what are the parents' need for support and services (Llewellyn, 1995a; Llewellyn, 1995b). This presentation discusses one component of a research project conducted in 1995 with Federal International Year of the Family grant funding.

Parent Support and Services Project

The overall aim of the project was to investigate the support and service needs of parents with intellectual disability.

The research design incorporated:

- interviews and questionnaires with parents
- questionnaires with significant others and service workers nominated by the parents
- focus groups with specialist service providers
- survey of generic (mainstream) service providers

This presentation addresses the findings from the first two parts of the study - the findings from parents and their nominated significant others and service providers.

Participating parents

Parent criteria for inclusion in the study were as follows:

- formal diagnosis
- designated as intellectually disabled by health or welfare professionals
- ten point checklist (developed by Kaminer, Jedrysek & Soles, 1981).

52 parents (40 mothers and 12 fathers) participated in interviews. Of the 12 fathers, five took part in interviews with their partners, however, data on their individual service needs was not

collected. Therefore, all findings refer only to 47 parents (40 mothers and 7 fathers) for whom there is individual demographic and interview response data.

In virtually all families, the mother was the primary caregiver. In a few families parents emphasised sharing primary child care responsibilities. Two thirds of the parents lived in metropolitan areas; with one third coming from rural areas. A small percentage were single mothers. Most parents had one child, with the range of children being from 0 to 8 years. Nearly three-quarters of the children were young - under 5 years of age. Only five parents had one or more children 13 to 18 years and three parents had children over 18 years.

90% of the parents were dependent on welfare benefits for income. These benefits include Jobsearch or Newstart employment benefits, disability support pension, child disability allowance and family payment. Among those who did not rely on benefits, 4 parents depend on their partner's income, and 1 parent is employed full-time. Most parents (n =32) live in public housing.

The majority of parents had their children living with them. Six parents (12.8%) had one or more children taken into care. Some children lived with their grandparents, others lived with foster families.

A Parent Interview Booklet was developed for this project. The booklet has four sections:

- demographic data
- Social Network Map and Grid (adapted from Tracy and Whittaker, 1990)
- Support and Service Use and Needs Survey (adapted from Walton-Allen and Feldman, 1991) and,
- Parent Wellbeing Scale (adapted from Johnston & Mash, 1989).

This presentation only relates to the data from the Support and Service Use and Needs Survey. This survey was adapted from one designed for the Canadian context in 1991 by Nicole Walton-Allen and Maurice Feldman. The adapted survey contains a total of 20 items divided into 3 domains of parenting skills as follows:

Support and Service Use and Needs Survey

Child care
child development, child stimulation, child discipline, child hygiene, medical emergency and home safety

Domestic
nutrition, food shopping, food preparation, cleaning house, money management

Social and community
assertiveness, marital relations, vocational skills/training, using community resources, friendships and leisure activities.

Additional items
respite, activities for the children and transport.

Methods

Each parent was interviewed and asked about the help they received or wanted on each item of the support and service use and needs survey. At the end of the interview parents were asked open-ended questions about whether they had received or needed help with anything else and what they liked and did not like about the help they had received.

Each parent was also asked to nominate a family member or friend referred to as a significant other and a service worker who was helpful to them. Of the 47 parents, 15 did not or were not able to nominate a significant other. This finding is consistent with other studies which suggest many parents with intellectual disability have little informal support from family and friends. Nine parents did not nominate a service worker. This was surprising as parents were primarily located by contact with service agencies.

Significant others

Twenty-eight questionnaires were sent to significant others, and fifteen (54%) were returned. Of these, 60% were family and 40% were in the friends category. Family members included the parents own parents or parents-in-law or their siblings. The friends category included advocates as well as friends.

Service workers

Thirty-seven questionnaires were sent to service workers, and 26 (70%) were returned. Of these, 42% were specialist workers and 27% workers from generic agencies. The remaining 31% included a group home manager, a supervisor in a sheltered workshop and a coordinator of a church-affiliated leisure group.

The questionnaire for significant others and service workers is similar in format to the Parent Interview Booklet. The three sections include items from the Social Network Grid; items from the Support and Service Use and Needs Survey and finally, an open ended question inviting respondents to share their experiences in helping the parent.

Analysis

Data analysis in this part of the project was conducted in three phases to incorporate both quantitative and qualitative data. Frequency statistics were used to calculate percentages for help needed and help received. The Kruskal Wallis Anova and the Friedman Two Factor Test were used to determine between group differences. Constant comparative analysis procedures were used for the open ended, qualitative data.

Results

The first finding is about areas of parenting with which parents need help.

Child care

The greatest proportion of parents (63%) reported needing help on one item, child development. Child development was also the greatest area of need for parents as determined by service workers (80%) and significant others (60%). Child stimulation and child discipline were also

reported as areas of considerable need by all three groups.

Domestic
Need for support in the domestic domain was relatively low except for money management. 58% of service workers thought parents needed support with nutrition.

Social and community
A greater percentage of parents reported needing help with using community resources (50%) and vocational skills/training (45%) relative to other items. Service workers (72%) and significant others (58%) also identified a relatively greater percentage of parents as needing help using community resources.

Additional items
A greater percentage of parents reported needing help with accessing activities for their children, and respite care relative to other items.

The second finding is about the significant gaps in the help received by parents.

Parents reported needing significantly more help than they were currently receiving in the social and community domain (chi square = 9.38, df=1, $p<.003$). From the parents' perspective, the greatest gaps in help are for vocational skills/training such as exploring work options for the future; accessing community resources which means knowing what services are available and how to use them; and friendships, which was defined as meeting people and making friends.

In addition, the child development item stands out with 63% of the parents reporting needing help and only 37% of parents currently receiving help in this area.

The last finding is about whether parents and their service workers and significant others perceived parents' needs for support and services differently.

The answer is that all three groups were generally consistent on the help they thought parents needed. The Kruskal-Wallis One-way Anova was used to examine differences between the three perspectives on parent needs within each domain. No significant differences between groups were found in any domain (p-values .15, .50 and .59). However, service workers did identify a greater percentage of parents needing help than parents did themselves on 90% of the items.

Parents' were also asked about what they liked about the help they received
There were three main areas in the types of help that parents liked.

Someone who cares ...
People who visit, telephone, help out, listen
Someone to talk to - another person who has children
A place to share problems and talk about solutions
Someone who doesn't wait to be asked to give help

Practical help...
Getting the kids into a better routine - getting jobs done around the house
Assistance filling out forms, lifts to appointments or shopping, food vouchers, giving baby clothes
Making explanations simple

Help for the children...
Therapy, medical help, home care
Easy to understand explanations about child problems
Organising activities for children to have fun and for parents to have a break
Involving parents in decisions about their children

Parents were also asked about what they didn't like about the help they received
Again, there were three main areas.

"I don't like it when they boss you around!" This includes:

Being ordered around by others
Not being respected, especially in own home
Overriding parental decisions
Being told what to do rather than asked
Lacking choice and losing control of making decisions

"Help that is no help". This includes:

Asking for advice and being given detailed and complex answers
Being rushed and not being able to keep up with the instructions given
Being treated as if not knowing how to care for children
Being told to "just fill out the form" when illiterate
Being given different and often conflicting advice

"You will get into trouble". This includes:

Feeling threatened about losing their children
Not trusting service workers
Being treated like a child
Constant intrusions in family life

"I feel like they left town for me". This includes:

Feeling abandoned
Asking for help and waiting a long time
Being promised help that falls through
Ringing and always getting the answering machine
Workers cancelling appointments
Receiving help, but not often enough to really help
No one to turn to when needing help

Significant others

Overall, responses from the significant others indicated a strong desire to support the parents who nominated them. These responses were very personal as they related to each individual nominating parent. The most outstanding feature of the help given by significant others was the contextual factors which have an impact on this help. For example, family and work commitments, age (particularly relevant for aging grandparents) and geographical location especially when parents and their significant others were separated by considerable distances.

Service workers

Service workers' written comments vividly portrayed the ups and downs of providing support to parents with intellectual disability. The substantial rewards as well as the untold frustration were evident.

Services workers' said the best part of their experiences with parents included:

Seeing parents' coping skills develop over the years
Knowing that so often new parents want to do the best job possible but sometimes do not know how to go about it
Enjoying the relationship with the parents
Watching parents work so hard to make sure their children get what they need
Seeing mothers with intellectual disability, as single parents, manage as others do with extended family support

Service workers' said the worst part of their experiences supporting parents included:

Being wary of calling Child Care and Protection for fear of child removal
Trying to balance parents' interests and childrens' best interests
Not being able to provide close support as a family would because of limited time but also because of not being "family"
Watching parents becoming frustrated with their own lack of ability and little support from others
Seeing parents being timid with their children for fear of doing something wrong

Service workers' concerns about services

Service workers wrote about the restrictions that limit giving parents the ongoing and intensive support that they require. There were three major concerns:

- lack of time with high caseload
- not being able to provide the practical day-to-day help parents need
- lack of community services willing and able to provide in-home practical help.

In their responses, service workers offered suggestions for how support and services should be made available for parents with intellectual disability. Five features were consistently mentioned. These were that services needed to:

- occur in the parent's home
- work on short term achievable goals
- be positive and encouraging
- be practical and involve demonstration and repetition
- link into mainstream services for parents and children

Summary

The findings highlight major areas of parents' needs for support and services.

The first major area of help needed is with child development.

That parents need help with child development is not surprising. Most parents with intellectual disability have had *restricted life opportunities*. The segregation they experienced at school continued outside the school yard. Different expectations were held for them when they were children and as young adults. Parents with intellectual disability mention how their families never thought they would become parents. No one talked to them about "when you grow up and have children". Although sex education and pregnancy prevention is now, in most instances, included in school curricula, developing intimate relationships and being parents are not always considered as a possibility. Certainly, for the parents in our study, talking about their rights and the responsibilities of parenthood was not part of their upbringing.

The second major area of help needed is with using community resources

Parents with intellectual disability are questioned *consistently about their parenting*. Other people regard parenthood differently when parents are intellectually disabled. These parents are frequently judged incompetent before they have a chance to prove otherwise. Judgements focus on whether the parents provide adequate physical care and stimulation for their child. Children may be removed irrespective of whether parents have been given any opportunity to learn child care skills.

Not surprisingly then, many parents are reluctant to use community resources for themselves or their children for fear of retribution of some kind. Add to this the parents' difficulties with literacy, transport, and assertiveness skills and it becomes clear why many parents do not attend services at all or attend infrequently.

The last major areas of help needed are with vocational skills and training and help with friendships

The *general impression still held by the community* about people with intellectual disability is that they are not regarded as sexually mature, but rather as perpetual children. They are considered incapable of fulfilling certain adult roles particularly those which demand complex skills. Parenting is an obvious example of this. Parenting requires many personal, social and community skills. The more severe the person's difficulty with learning, it is thought, the less likely he or she will develop these everyday skills.

Agitation for the rights of people with intellectual disability and subsequent legislation and policy are bringing some changes in these attitudes. Many adults with intellectual disability do participate now in everyday community activities: they live, learn, work and enjoy leisure in community settings.

However, their personal care skills, their awareness of safety issues and their social behaviours may continue to attract undue attention. Under these circumstances it is almost impossible for many parents with intellectual disability to be accepted into community groups, to get out and about, to meet people and make friends and to be given opportunities to develop vocational skills all of which were significant needs for the parents in this study.

Conclusion

In conclusion, developing support and services to meet the three major areas of parent need presents a considerable challenge to planners and to service providers. None of the areas are amenable to short term, quick fix solutions.

For parents needing help with child development, this will continue over the long term. Children change over time and their needs change. Learning about managing your child at different stages and ages is an ongoing process. At certain critical times such as when children start school and enter puberty, parents will need additional assistance.

The second area of identified need, learning to use community resources also takes time. This is particularly so when many community resources are not accessible for people without literacy skills and who lack transportation or the ability to use existing transport systems.

The third area of identified need is help with friendships. Developing friendships is particularly difficult for parents already suffering social isolation, and in many instances, lacking a supportive informal family or neighbourhood network.

The final area of identified need is help with vocational skills and training. That parents identified help with work related activities is not surprising when the majority were dependent on benefits. There are vocational training opportunities for people with intellectual disability however, these may be less accessible for parents particularly when they have preschool or school age children.

The findings from this study provide for the first time, in Australia, parents' views and the views of the people closest to them about the support and services that parents need and want. The challenge before us is to make sure that the services offered to parents are based on what the parents themselves, and their significant others and service worker, have identified that parents need. Five principles of support and service provision have been developed from this study. These are:

- Services need to be responsive to parents' individual needs
- Services need to support parents over the long term
- Services need to provide opportunities for parents to learn in their own time and in their own way
- Services need to help parents become part of their local community
- By supporting parents, services also support their children

Each of these principles has been incorporated into the following specific recommendations aimed at providing appropriate, efficient and effective support and services to parents with intellectual disability in Australia.

Recommendations

Recommendation 1: Intensive, individualised support

Mainstream services must incorporate an individualised service planning approach in their work with parents with intellectual disability and ensure that parents are active partners in this process.

- Services need to incorporate procedures into their service planning which involve parents in selecting and setting personal parenting objectives. Parents learn best when their views about what they need to learn are taken into account.
- Services need to take into account the special instructional needs of parents with intellectual disability. People with intellectual disability learn best when tasks are demonstrated and when there is opportunity for ample repetition.
- Services need to plan instructional activities in naturally occurring situations. Parents learn best about parenting in the family home when the task is practical and is taught in the situation where it typically occurs.

Recommendation 2: On-going funding

Mainstream services require the necessary funding to provide ongoing, long term support to parents with intellectual disability

- Services need sufficient resources, specifically allocated, to ensure that the long term needs of parents are met.
- Services need sufficient resources, specifically allocated, to incorporate a preventative and proactive focus in their work to forestall a cyclical crisis orientation to working with parents with intellectual disability.

Recommendation 3: Family-centred focus

Mainstream services need to incorporate a family-centred focus in their planning for parents so that the needs of the family are met. Specifically resources need to be devoted to not only meeting parents' parenting needs but also to meeting their personal development needs.

- Services need to continue to address child-related topics of relevance to parents in particular child development, child stimulation, child discipline and activities for children.
- Services need to specifically address parent-related topics especially in personal development skills such as meeting people and making friends, developing literacy skills and vocational skills and training.

Recommendation 4: Accessible, available services

Mainstream services must have adequate resources to make sure services are physically accessible, widely known about in the community and welcoming to parents with intellectual disability.

- Training for mainstream agency workers needs to incorporate information about place of other agencies in supporting parents and to help workers develop skills in advocating for parents in the wider community.
- Services must be specifically funded to provide transport as necessary so that parents can attend

- Services must be specifically funded to develop and distribute plain English information and alternative forms of information for non-literate parents and those of Non English speaking background.

Recommendation 5: Supportive environment for parents

Mainstream agencies must be specifically funded to undertake an educative role with parents to assist parents to create an environment which supports children.

- Training for mainstream agency workers needs to incorporate information about parenting, about intellectual disability and about the impact of intellectual disability on learning parenting skills.
- Services must be specifically funded and designated to provide proactive parent education particularly in relation to identified "difficult" times such as the transition from home to school and primary school to high school.
- Services need to allocate funding to developing parent support groups where parents can exchange information in a supportive atmosphere and practice alternative strategies for managing difficult behaviours.

Recommendation 6: Inter-agency collaboration

Inter-agency collaboration must be specifically acknowledged as an essential element in providing support and services to parents with intellectual disability.

Inter-agency collaboration must specifically promote:

- family centred focus in contrast to a parent-only or child-only focus
- preventative work rather than crisis intervention
- access to mainstream services for parents and their children rather than reliance on specialised support services.

Recommendation 7: Data collection

The collection and dissemination of epidemiological and support and service needs data about parents with intellectual disability and their children must be commenced as an essential part of planning and providing services. Collection and dissemination of adequate data requires inter-agency collaboration to ensure that the data collected reflects not only those parents and their children known to specialist services (in particular, disability and child protection services) but also parents with intellectual disability and their children more broadly in the community.

Collection and dissemination of data must specifically address:

- the number of parents with intellectual disability in the community (prevalence)
- the number of people with intellectual disability becoming parents in any given year (incidence)
- the level of support needs of parents and their need for services
- the geographic location of parents, and
- the number of children in families headed by parents with intellectual disability, and their need for support and services.

Recommendation 8: Pilot project

Finally, it is recommended that funding be specifically allocated for a local community-based pilot inter-agency project to investigate the most effective way to develop and maintain inter-agency collaboration in provision of services to parents with intellectual disability.

This pilot inter-agency collaboration project would be expected to draw together government and non-government agencies responsible for services to parents and children in the areas of, but not limited to health, community services, disability services and education.

In addition, this pilot project would be designed and implemented according to the principles elaborated in the first five recommendations as follows:

- incorporating an individualised service planning approach
- building on specifically allocated resources to meet long term needs
- providing a family centred focus
- ensuring accessibility and availability to parents most in need
- supporting parents to create a safe, nurturing environment for their children.

It is strongly recommended that this pilot project be conducted as a research and development activity to ensure an empirical foundation and evaluation outcomes.

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